



# When Reproductive Freedom Encounters Medical Responsibility

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# When reproductive freedom encounters medical responsibility: changing conceptions of reproductive choice

SIMONE BATEMAN

## Introduction

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Sex is no longer the only means of conceiving human beings. Ever since artificial insemination was first used two centuries ago, a pregnancy can be obtained through the use of techniques generally referred to as reproductive technology<sup>i</sup>. These techniques have created new options for persons who would otherwise not have had children, but they have also progressively altered the practices and relationships that condition and give meaning to reproduction in our society. This is primarily because reproductive technology is most often made available in a medical setting, where relationships are defined in therapeutic terms, where values give precedence to the quality, security and efficiency of a technical act, and where physicians are held responsible for the appropriate management of procedures. Impregnation no longer has to do with the privacy of one's sex life, but with the accomplishment of a medical act. This turning over of conception to professionals deemed competent in reproduction leaves some would-be parents disoriented and even feeling dispossessed of their customary (often felt to be "natural") liberty to make reproductive decisions (*1*).

Reproduction is today firmly established as an area of legitimate medical intervention; we must remember, however, that the presence of a (usually male) physician at childbirth dates back in Western Europe to only two centuries—a presence whose sole initial justification was the medical monopoly of a new instrument, the forceps, designed to facilitate difficult births. More recent techniques and procedures in the area of obstetrics and gynaecology, such as contraception, abortion, the monitoring of fetal growth or testing for fetal abnormalities during pregnancy, have since helped solidify physicians' claim to professional competence in this domain. Nonetheless, most of these techniques have given rise to much controversy: the idea that it is legitimate to control or interfere with conception and gestation, even under medical auspices, is far from being a consensual issue in many societies.

In most countries, assisted reproduction technology (ART) was originally introduced to treat infertility. Today it is also being offered to fertile heterosexual couples as a means of avoiding the risk of transmitting hereditary disease to their offspring. Both of these circumstances are generally recognized as legitimate indications for treatment. Occasionally

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<sup>i</sup> This term can be applied more generally to include all kinds of techniques, including contraception and abortion, whose purpose is to control or otherwise intervene in the reproductive process. In this paper, we are restricting its use to designate only those techniques whose ultimate objective is to initiate a pregnancy.

fertile heterosexual couples have resorted to ART as a solution to unusual circumstances (such as couples wishing to select a compatible embryo as an organ donor for a living child) (2). Single women and lesbians have also used donor insemination (DI), usually without medical assistance, as a valid alternative to sex for conceiving children. These latter uses of ART remain morally controversial in many countries. But whether or not an infertility problem exists, the question of medical responsibility will invariably be raised whenever a physician is asked to intervene.

Most societies grant physicians considerable authority in deciding what is to be regarded as the best way of implementing a medical procedure; they thus play an important role in defining the values that guide the use of new technology. However, medical reproductive and related genetic practices are procedures whose immediate objective (conceiving a child) and ultimate consequences (demographic, psychological, economic, etc.) are not normally included in the usual scope of a physician's professional competence and responsibility. A physician's involvement in a patient's choices about sexuality and childbearing quite obviously bring into play a broader scope of values than those immediately linked to the professionally responsible practice of medicine—values usually embodied in moral convictions regarding what constitutes a “good” life in terms of sexuality and procreation, family life, health and handicap. The legitimacy of medical authority in this domain may therefore be open to question, creating possibilities for conflict with conceptions of reproductive liberty.

Reproductive liberty (3) can be defined as the freedom to make essential choices affecting one's reproductive life. A major decision involves choosing whether or not to have children which, in the case of an affirmative answer, implies decisions concerning with whom, when and in what circumstances. Of course, having children is not necessarily the result of a conscious decision-making process: social pressure, interpersonal conflict and personal ambivalence often interfere with complex biological processes not totally under our control, making the final result of our reproductive lives quite different from our original plans. A couple's decision to have a child by no means guarantees that they will ultimately have one, even when they appeal to medical assistance. Nonetheless, the development of techniques the purpose of which is to increase control over the consequences of our sexual lives and the different aspects of our reproductive decisions—whether or

not, with whom, when and in what circumstances—has reinforced the idea of reproduction as a project and a consciously controlled process.

But this increase in control paradoxically requires entry into a new type of reproductive relationship, loosely if not inappropriately defined as therapeutic. Infertility is not strictly speaking a disease: it is certainly a personal and social handicap for the person who is thus affected, but it is not a life-threatening disease. Moreover, the concept of infertility which underlies current use of reproductive technology is a peculiar construct, in which medical and social criteria are closely interrelated: it describes as unable to conceive, not a person with a medically proven infertility problem, but two particular persons—a couple—who are unable to conceive a child together, because one or both are infertile. Treatment, however, invariably concerns the woman, even when she is not infertile, as she is the child bearer. Both DI and intracytoplasmic sperm injection (ICSI) make this point particularly clear: the procedure is carried out on a fertile woman, who could have become pregnant, had she chosen to do so, by having sexual relations with another man. In fact, infertility is a relative concept whose limits are difficult to define: very few patients are diagnosed as completely sterile, and a person diagnosed as infertile might have been able to conceive, had he/she found a more fertile partner.

The fact that infertility is not a disease does not mean that physicians should not try to treat the condition. But assisted conception cannot be considered a cure for either male or female infertility: neither artificial insemination nor *in vitro* fertilization (IVF) enable their infertile beneficiaries to conceive a child on their own. In fact, although these techniques are commonly presented as medical treatment, they constitute an evident deviation from the standard approach to healing. Medical treatment aims, when possible, at identifying and eliminating the cause of a pathological condition: this may be the case in the first phases of an infertility work-up and treatment. When diagnosis has failed to determine a cause, or treatment to provide a cure, a physician can attempt to eliminate or alleviate the symptoms of a disease by some form of palliative treatment. Assisted conception does address infertility's primary symptom, the absence of a viable pregnancy, by replicating a defective function it cannot cure. This, however, creates a totally unprecedented therapeutic position in that the immediate medical objective goes beyond the alleviation of suffering: the aim of reproductive technology is to

conceive a human being.

Medical assistance with conception thus consists essentially in providing technical expertise in fertilization and impregnation, a task that transforms physicians, so to speak, into professionally competent reproductive partners. As such, they find themselves called upon to intervene in many crucial procreative decisions. These choices and decisions are all the more difficult to make, in that the facts that inform them are still being accumulated or exist only as probabilities. Moreover, the complexity of the therapeutic relationship, to which must be added the problems raised specifically by the physician's involvement in a reproductive act, concur to create potential for conflict in which it may no longer be evident who, in this novel reproductive framework, should be making fundamental decisions about the coming into existence of a child. Should they be made by those who, as professionals, carry out fertilization and impregnation; by those who, as donors, contribute the reproductive cells; or by those who, as future parents, will ultimately assume responsibility for the child to be born? Deciding who will decide in case of disagreement may involve weighing the physician's responsibility for the safety and the favourable outcome of the procedure against the patient's freedom to make reproductive choices.

Many would-be parents do not consider it necessary to justify their request for assisted conception: the reasons they wish to have children and the conditions in which they intend to raise them concern their private life. But numerous physicians feel that, given their responsibility as professionals, they should refuse or discontinue assisted conception, if they consider that the conditions in which the child is to be born are unacceptable. When would-be parents do not acquiesce to the physician's point of view, a conflict arises which usually leads to attempts at arbitration: in France, this usually means the intervention of a psychologist, referral to an ethics committee, or recourse to a legal procedure (4).

Conflict may arise over questions of access to reproductive technology, in particular with respect to atypical requests for reproductive technology. But even in more conventional situations, there may be conflict over the procedure considered most appropriate, or over the best solution to unforeseen consequences of an otherwise consensually decided procedure. Even though physicians, would-be parents and even donors (5) are all apparently endeavouring to achieve the same goal—the birth of a child—there

may be significant differences in the way each protagonist approaches this goal. Regardless of the differences among protagonists involved in a conflict, their respective positions often highlight a concurring moral preoccupation: in what physical and social conditions is it acceptable to bring a child into the world? Both physicians and would-be parents, in justifying their viewpoints, frequently refer to a child's best interest. This emotionally charged notion rarely conveys a precise content or meaning, although it does eventually serve to articulate normative concerns about a child's future. Ultimately, the various versions of this argument reveal competing visions of the person, the family, and of life in society; their impact on the future of childbearing will depend on the priorities established among these arguments as conflicts are resolved.

## Deciding to have children

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One of the main points of conflict between would-be parents and professionals—and usually a major issue on the political agenda—is the type of situation in which reproductive technology may be legitimately requested. Generally speaking, there are two sorts of requests. The first usually comes from heterosexual partners who, unable to achieve a viable pregnancy, seek medical help. Assisted conception is offered in these cases to compensate for a couple's physiological incapacity to reproduce, thus bringing society's support to the conventional (often perceived as the "natural") means of founding a family. The second type of request, more controversial but arising from the very existence of these techniques, comes from persons who do not wish to entertain heterosexual relationships (single, divorced or widowed men and women, gay and lesbian partners), but who nonetheless wish to have children. Providing assisted conception in these circumstances recognizes as legitimate the wish for descendants of those who refuse marriage, partnership or heterosexuality as a way of life and as the only suitable framework for raising children.

In many countries, only the first type of request is considered a socially legitimate reason for access to reproductive technology. Indeed, the whole notion of infertility treatment has been constructed around this indication. And yet, despite apparent differences between these two types of request, they do seem to have three points in common: (i) the wish to avoid sexual relations considered personally, socially or

morally unacceptable and the emotional complications they might entail (fidelity to one's partner appears as a common concern); (ii) the wish to overcome the limitations imposed by one's personal and sexual preferences, in particular that of having chosen an infertile partner or form of relationship; and (iii) the wish for *a child of one's own*, understood as a child emanating from the would-be parents' body and/or gametes. These three points often justify the first type of request, but in many countries, they often invalidate the second. But if they are considered problematic in one case, why is this not true in the other?

The distinction between appropriate and inappropriate requests evidently uses the fecund sexual relation between a man and a woman as the normative model of procreative behaviour—a model that supposedly refers to a “natural” order of procreation. In France, article L. 152-2 of the French 1994 bioethics law draws on this model, as well as on the social value attached to voluntary procreation within a stable relationship, to establish, apparently without ambiguity, the conditions in which assisted conception may legitimately be provided:

The purpose of assisted conception is to respond to a couple's request to become parents. Its objective is to remedy infertility, the pathological nature of which has been medically diagnosed. It may also be used to avoid transmitting a particularly serious disease to a child. The man and the woman who form the couple should be alive, be of reproductive age, married or able to prove at least two years of cohabitation, and they should give previous consent to the transfer of embryos or to insemination.

[my translation]

The attempt to anchor the legitimacy of assisted conception on the supposedly natural norms of human reproduction (participation of two live persons of different sex and of reproductive age) disregards the manner in which society intervenes to redefine what is natural in humans. To give an example, the age at which it is physiologically possible to have children does not necessarily correspond to the age at which it is considered socially acceptable to have them. A physician would probably not offer assisted conception to an infertile adolescent couple. The biological norms of reproductive capacity are always reassessed

in the light of social norms defining the aptitude to become a parent. Even a distinction as biologically evident as morphological sex differences can turn out to be an ambiguous criterion, in the rare cases in which a person has an anomaly of the sexual organs or has undergone hormonal and/or surgical transformation of his/her sex. Sexuality itself is reduced, in this perspective, to its species-oriented function: reproduction.

Legislation thus conceived aims to exclude all normative options that might define assisted conception as anything other than an exceptional venturing away from the “normal” ways of founding a family. The use of reproductive technology as a procreative alternative to sexuality is perceived as too radical an option, with unknown social consequences. And yet the very notion of what constitutes a family has already been profoundly affected by the increase in divorce and remarriage, by the growing number of non-married couples and of same-sex unions. Recent USA census data (6) indicate that less than a quarter of the households are made up of married couples with children, whereas the number of families with children but no spouse present are increasing, a trend which is now much advanced and well established in European countries. Procreative plans and behaviour have also undergone considerable change with access to earlier forms of reproductive technology, such as contraception and abortion. And single women, gays and lesbians did not wait for reproductive assistance to have children: many made special sexual arrangements to achieve their purposes and invented new forms of parental relationships with their children (7). Of course, DI has contributed in making these procreative possibilities seem more attractive, particularly to those who wished to dispense with opportunistic sexual relations. And some procreative options were not possible as long as conception took place entirely within the body. Indeed, IVF now allows for heretofore unimaginable dissociations of the reproductive process: the possibility for two separate forms of biological motherhood (8), the separate gestation and birth of embryos conceived at the same time, reproduction with only one or with three sources of gametes (9,10). But many changes in the contemporary family cannot be attributed to these procreative innovations.

The family has never been a natural unit; nor can it be considered the social expression of the biology of reproduction. Family forms have varied considerably through time and space, and, in many societies,

socially and legally sanctioned kinship relationships do not necessarily reflect the biological ties between persons. In many contemporary societies, it is true that the legal ties binding the spouses in a marriage usually carry with them the expectation that the spouses will also be the genitors of the children born to that marriage. This expectation has for centuries rested on the moral value of sexual fidelity. But what institutes the parental tie is a legal act, and not a biological one: even when a society decides to give precedence to biological ties in establishing parenthood, this is a social decision with its corresponding justifications and not an imposition on society of an incontrovertible biological fact (11). Of course, as knowledge accumulates about the facts of reproduction and heredity, our own societies may be attributing an increasing importance to biology in their thinking about the family. The tendency is then to confuse scientific truths about conception and heredity with the social and legal organization of family ties and the emotional and physical experiences underlying the quest for children. As biological metaphors and metonymies for kinship relationships flourish, evolving from the outmoded notion of blood ties to the more scientifically modern notion of genetic ties, we forget that these expressions only signify a more complex whole.

Given that humanity has known so many family forms and been so inventive in finding solutions to the lack of descendants, it is difficult to give credence to the idea that the "traditional" family is in danger. The traditional family may simply be a normative ideal that uses the nuclear family as a landmark to provide social bearings in times of disquieting change. The disadvantage with this approach to innovation is that it defines outright all novelty as unethical or unsafe, while disregarding what may be morally questionable in familiar circumstances. Even if unprecedented options disrupt our usual social and symbolic landmarks in thinking about procreation and the family, they do not, for that reason, threaten our humanity. They do make it vital to rethink the anthropological foundations of procreation in the light of new options.

Whether science and technology represent a threat to family relationships and to social stability may have more to do with our reasons for implementing these new techniques than with the idea that we may, unwittingly, be destabilizing natural human phenomena. The risk of interfering with and destabilizing biological mechanisms is real and should not be minimized, but it is a scientific issue in its own right,

related but separate from the issue concerning the way a society deals with limitations imposed to human aspirations by the body and by the environment. The best way to approach the ethical issues concerning the effects of reproductive technology on children and their families may be to examine, not hypothetical options, but those already available and considered acceptable, with the unforeseen problems they raise. We may not have sufficiently explored and understood the novelty of familiar situations and, in particular, the role medicalization plays in that novelty. Some of these issues may have an effect on the family and on procreation that is more profound than is immediately evident: in fact, we may have already gone beyond the controversial issue of whether or not persons in unconventional family situations should use reproductive technology to have offspring. The way decisions are being made about current difficulties may give us clues to underlying trends, and thus to the social choices we are really making.

At first glance, occasions for conflict in situations where the persons being treated are an infertile heterosexual couple appear to be less frequent and less radical. There are nonetheless numerous examples illustrating that, even in the most conventional indications, unforeseen incidents can create difficult ethical dilemmas. I speak of dilemmas purposely, in that many of these situations seem to have no best solution: they either open a choice between two equally unknown possibilities, or offer an option between familiar but inadequate normative references and novel references whose normative pertinence is as yet unknown.

Not all issues underlying decision-making in this area can be handled within the confines of the therapeutic relationship. Some may ultimately call for discussion and decision-making at a political level, the results of which will be diversely affected by the pertinent social, cultural and economic context in which a reproductive procedure is being introduced. In other words, at the heart of the moral issue that involves choosing the best solution for all the protagonists involved, is the social issue of deciding what is the best framework for ensuring the desired outcome.

## Avoiding harm and taking risks

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No matter how conventional the familial situation of those who request procreative assistance, reproduc-

tive technology involves would-be parents in unprecedented ways of engaging their sexuated bodies in a procreative relationship. Reproductive experience is dismembered and extended in time and space, especially when conception is externalized. This multiplies the number of reproductive events calling for decision-making, and thus the occasions for unforeseen incidents and conflict. The persons directly involved in the conception of a human being are also more numerous: they are not only the would-be parents, but also the professionals technically competent in reproduction and eventually the donors of reproductive cells. If all the protagonists share a moral obligation to act rightly with respect to themselves and to others, those intervening as specialists have an added obligation to provide care meeting the standards of the profession.

Ensuring the quality of medical attention provided to patients requires a translation of this general principle into concrete technical choices. In strictly defined therapeutic situations, these choices usually reflect a consensually defined approach to disease prevention, in harmony with professional standards and guidelines for a particular act; they also ideally reflect the medical staff's basic ethical stance of beneficent action in caring for patients. In the case of reproductive technology, physicians additionally control access to essential technical and biological resources that make fertilization possible in a medical setting; they thus exercise discretionary powers in basic reproductive decisions, in particular in cases where procedures require choosing an appropriate reproductive partner—an egg or a sperm donor. There is still much discussion among physicians concerning the criteria on which these choices should be based and the responsibility associated with the consequences of these choices.

Concretely, questions about medical responsibility usually arise in situations which involve risk-taking, and in which the protagonists hold differing views of what constitutes an acceptable risk in the light of expected benefits (12–14). In reproductive procedures, eventual risks first concern the woman's health, as she is the primary patient. As such, many questions raised by conflict between conceptions of professional responsibility and of patient autonomy do not differ essentially from those raised in a traditional therapeutic situation. But as mentioned earlier, infertility is not a life-threatening disease, nor is assisted conception treatment for infertility. Failure to intervene cannot be said to endanger the woman's

health, as might be the case in some routine therapeutic circumstances, whereas there may be important risks in undertaking the procedure. Many forms of assisted conception are physically and emotionally trying experiences for women; they do not always result in a live birth, or may do so only after repeated attempts. Many women may, nonetheless, feel that not having access to the procedure at all could provoke personal distress that is just as serious.

What makes matters even more complicated is the fact that medical concern with risk-taking in reproductive procedures tends to include an, as yet, non-existent third party, the unconceived child. Should professional responsibility for the competent management of a reproductive procedure be guided by the endeavour to do anything more than simply avoid procedures harmful to the woman's health and life? The question is raised acutely in cases where there is a risk that the child will be born with a serious disorder. When such a risk is inherent to the procedure, it is in most cases relatively uncontroversial to stop providing it. But when the risk for harm derives from the medical and the social background of the genitors, the medical stance considered most appropriate is far from consensual.

Establishing a medically appropriate response to a person's request for assistance with conception may be approached either as a question regarding legally defined medical responsibility or as a broader concern with moral responsibility. From a legal perspective, a physician in normal therapeutic circumstances is obliged to propose the necessary means to restore health, but is not held responsible for the outcome of treatment, if the procedure has been performed correctly. In certain situations, physicians occasionally experience these minimal legal requirements as insufficient from a moral perspective. In the case of assisted conception, physicians may even feel that the reverse relationship is true: physicians should not be obliged to propose systematically the means of conceiving, but may be held responsible for the outcome (12–15).

In both perspectives, the fundamental question remains the same: in so far as reproductive technology is not, strictly speaking therapeutic, what criteria define the competent and responsible enactment of a reproductive procedure? An answer to this question requires agreeing on what is the outcome of that procedure. The immediate objective is a viable pregnancy, for as long as this objective is not attained, the procedure will be repeated. There might however

be a limit to the number of times a procedure may be attempted, without harm to the patient. But when the procedure succeeds, does the physician's accountability stop there? Or is the physician ultimately responsible for the state in which the child will be born? If the latter is the case, to what extent is this true? Quite obviously, different definitions of the outcome of a procedure affect working conceptions of appropriate action.

Three recurrent dilemmas are encountered by physicians in routine practice. These dilemmas often oblige them to reconsider the assumptions on which their practice is based. In many cases, the dilemma will first arise as a technical problem requiring a professional response, but as physicians try to solve it, the social and ethical significance of the problem comes to the surface. In some cases, they become a source of conflict with patients. Their immediate solution does not seem to involve finding a right answer, but reaching an agreement among all concerned as to how the priorities in decision-making will be distributed throughout the procedure. This implies identifying the possible consequences on the child and the family of each solution and on whom the responsibility for these particular consequences will rest. The three dilemmas are as follows.

### ***1. In what circumstances is the transition from sexuality to assisted conception justified?***

This problem arises in routine practice with both fertile and infertile couples. In the case of infertile couples, the question essentially involves deciding when one should consider that treatment of infertility has failed and that it is legitimate to go on to offer palliative solutions, such as assisted conception. One example of such a dilemma is choosing whether or not to try a curative option such as microsurgery of blocked fallopian tubes, which may not succeed, or go on to the palliative option, IVF. Another is whether or not therapeutic action should be delayed, such as in cases of low fertility where there is a statistically significant chance that a couple might conceive. Medical attitudes vary with respect to this problem: some will persist in delaying treatment or attempting curative solutions if the chances for success seem reasonable, on the basis that restored fertility and thus reproduc-

tive autonomy is the best solution for the couple. Others may feel that precious time, in particular with respect to female fertility, may be lost with treatment of uncertain benefit, thus diminishing the chances of arriving at the essential objective, a live birth.

The problem also arises in the treatment of couples who request assisted conception with donor gametes to avoid transmitting a serious disease (such as HIV) or a hereditary disorder to the child. The couple is not infertile and, in the case of recessive hereditary conditions, each partner would have been able to conceive children without that particular risk had they been with another partner who was a non-carrier of the same trait. Moreover, when the male partner is the carrier, he must use some form of contraception during the period of insemination. Abstaining from using one's procreative capacities is often difficult to accept, even when one is perfectly conscious of the risks involved; in fact, on occasion, the child born after DI is afflicted with the disease, because no contraception had been used. In the case of a dominant hereditary condition, the problem is simpler to resolve: a vasectomy or tubal ligation permanently avoids the risk of transmitting a genetically determined condition. Assisted conception is then more easily justified on the grounds of infertility.

In the situations I have observed, contrary to what might be expected, geneticists and physicians are quite reticent to push a couple into a situation in which they must abandon the idea of conceiving on their own. They often prefer recommending genetic counselling and prenatal diagnostic techniques. The use of donor gametes is proposed only when no genetic testing for the condition is available, the genetic condition under consideration is *serious*, and the risk of transmission very *high*. They will also accept requests from couples having had to terminate several pregnancies after amniocentesis.

In all of these situations, it is the high probability of not conceiving a child at all or of conceiving a child stricken by a serious or life-threatening health condition that justifies the move to assisted conception. Physicians perceive the couple's sexual relations, even when the partners are fertile, *as being, for all practical purposes, sterile*<sup>ii</sup>. This approach to the problem validates medical interference in the intimate realm of impregnation. It often also validates the

ii It is my view that a definition of infertility, not as an individual incapacity to conceive (and bear) a child, but as an incapacity to produce a *healthy* child, will play a major role in the way both reproductive technology and genetic diagnosis and therapy will evolve as medical practices in the future.



exclusion of single women, lesbians, and women having reached menopause.

But there are other unusual requests that do not fit so neatly into one of the slots of this dichotomy. For example, most physicians would not refuse to treat any person with a medically diagnosed infertility problem, no matter what their sexual and relational preferences<sup>iii</sup> but many might balk at the idea of extending their services to assisted conception. Another example: although most physicians refuse to offer assisted conception to a menopausal women (who by definition cannot benefit from regular treatment for infertility), most physicians would find it unacceptable not to offer assisted conception to a woman whose premature menopause has been medically induced.

Some cases are highly controversial, even among physicians themselves. One interesting borderline case is the following: what if the persons requesting assisted conception are a couple in which the male partner is a transsexual?<sup>iv</sup> Here, as in the case of premature menopause, the infertility results from medical intervention that amounts to castration: the endocrinological and surgical transformation of a woman into a man. Those who oppose treating such couples feel that, just as in the case of single women or lesbians, the new situation created is not a “natural” situation of heterosexual infertility. But others feel that it is difficult to refuse a request coming from persons whose status as man and woman has been recognized civilly, sometimes even by marriage, and whose infertility is the result of recognized therapy for transsexualism.

Another example: is it a physician’s role to propose an alternative in circumstances that create obstacles to heterosexual relations? When these obstacles are related to physical health (for example, the husband is a paraplegic), physicians accept. But when the circumstances are social, such as employment that keeps a couple apart for great lengths of time, physicians tend to refuse. On some rare occasions, the competent administrative authorities in France have asked physicians to inseminate the wife or partner of a man serving a prison term, whose wife will have reached menopause at his release. Here the couple’s sterility is due to the social constraints placed on the heterosexual relationship, not only by the prison term,

but also by the fact that sexual relations are not allowed in French prisons.

The underlying dilemma in all these unusual situations remains the same as in the conventional situations: when is it justified to abandon sexuality for assisted conception? However, the question is no longer framed in terms of real or effective infertility, either because fertility is not a problem (single women, lesbians, separated couple) or because infertility is an accepted constitutional and socially recognized state (menopause, transsexualism). Most nonmedically motivated requests for assisted conception are founded on the idea of nondiscrimination in access to reproductive procedures. The question remains as to whether there are justifiable limits to free access.

If our societies decide to no longer restrict procreative possibilities to heterosexual relations or to medically justified procedures using marital heterosexuality as a normative reference, two problems are raised. The first requires rethinking our kinship relationships in such a way that they take into account all forms of procreation. The second requires reviewing a physician’s responsibility in situations where the demand for professional competence is restricted to implementation of a procedure, with practically no intervention in the area of diagnosis<sup>v</sup>. We must not forget, however, that, in the background, a definition of infertility, not as an individual incapacity to conceive and bear a child but as a conjugated incapacity to produce a healthy child, is probably playing a major role in extending the medical (and therefore apparently noncontroversial) indications for both reproductive technology and genetic diagnosis and therapy.

## ***2. To what extent is a physician’s responsibility involved when, in the context of assisted conception, there is a risk of harming either the woman or the future child through the procedure?***

As mentioned earlier, many of the responsibility issues in assisted conception are similar to those in any kind of treatment; they require an appropriate control of professional negligence by members of the profession through the setting of standards of practice. There is now relative consensus on how to handle some of the major risk problems of assisted

iii They might refuse to treat persons with a serious disease or a mental health condition.

iv These requests were first made in France in the mid-eighties. They have become more frequent in the past few years.

v This type of medical but nontherapeutic situation already exists with respect to contraception and abortion.

conception, such as ovarian stimulation and the number of embryos to be transferred to the womb after IVF (usually a maximum of three). But there is a tendency to disregard these standards when both physician and patient fear that caution will only be rewarded by the absence of a viable pregnancy.

Consensus is much more difficult to obtain when the risk involves transmitting a serious or life-threatening condition to the future child, because this risk is not immediately linked to the implementation of the procedure but to the medical history of its genitors (parents or donors). As we have just seen, physicians often perceive this risk as a justifiable medical indication for assisted conception even in fertile couples, as well as for screening donors to prevent the inadvertent transmission of disease. This screening in some countries, notably France, includes genetic screening of recipients, to avoid pairing a donor with a recipient who is a carrier of the same recessive trait. Most preventive measures taken in the interests both of the woman and the child are relatively uncontroversial (HIV testing of donors, for example); but can a physician go too far in attempting to prevent disease in children born through assisted conception? The disquieting spectre of eugenics raises its head.

The birth of a healthy child can never be guaranteed, no matter how many preventive measures are taken. Medicine's increased capacity to detect and eventually to prevent genetically determined conditions and malformations does not necessarily mean an increase in control over genetic parameters: they are too numerous, and the relationships between them too complex to be totally under control, even in a single specific situation. Physicians do nonetheless feel that, over and beyond their concern for their immediate patient, the woman, they can and must attempt to maintain the risks incurred by the future child at a limit defined as acceptable. However, the very task of defining such a limit in concrete terms is a complex and controversial process, even among physicians themselves. It is often quite easy for them to agree on the objective data that characterize a particular condition or a procedure, as well as on the objective data that describe the situation of the patient whose case is being considered. But evaluating the seriousness of a condition, the importance of the risk involved (is 5% or 10% a high or low risk?), and consequently deciding whether or not that condition justifies medical intervention (or on the contrary, refraining from intervening), requires subjective appraisal of objective medical data. At this point, the varied

clinical experience of physicians with their patients as well as their divergent professional and personal moral views come into play, making consensus as to what constitutes an "acceptable" risk, in some cases, an unattainable ideal.

For example, in the case of donor screening, many physicians feel that it is unacceptable to use the semen of a man certain or suspected of being a carrier of a *serious* genetic condition and, in the case of certain recessive conditions, that can be found *frequently* in the population, and for which there is a *high* risk of transmission. When the genetic origin of a condition has not been clearly established (for example, in the case of a donor who has been cured of cancer), they also feel that, in the absence of conclusive data, it is unacceptable for the physician to take the responsibility of accepting such a donor. Risk-taking here concerns someone else's offspring.

But is a physician responsible in the same way for the outcome of a pregnancy, when the risk of transmitting a genetically determined condition emanates from the parents' family history? In some cases, physicians discover that the woman, whose partner is infertile, is herself a carrier of a serious dominant condition, but which she only has in a minor form; this is often the reason why it was first overlooked. In other cases, she might be a carrier of a serious dominant condition (such as polyposis of the colon) which is a late-onset disease of variable penetrance. A more recent problem concerns the appropriateness of proposing ICSI to couples in which male infertility is associated with being a carrier of a statistically frequent and serious recessive condition, cystic fibrosis. Contrary to the situation in which it is decided to exclude a potential donor, because someone else's offspring will be affected, the decision to refuse assisted conception on the basis of the parents' family history, even when this attitude seems medically justified, is experienced by many physicians as a "questionable decision".

Is there a dividing line, and if so where, between the physician's responsibility for controlling the medical factors which intervene during a pregnancy and the couple's autonomy in decision-making regarding their reproductive lives? Does the fact that the birth of a handicapped child implies expensive medical treatment, usually paid for by the state, weigh as a valid counterargument against the fact that ultimately it is the parents who assume responsibility for raising the child? In other words, who assumes responsibility for the consequences of risk-taking in childbearing and how does this affect their right to decide?

These questions are raised most acutely in cases where an at-risk pregnancy is monitored with prenatal diagnostic techniques. The probability of giving birth to a child with a serious disease or malformation can be determined with certainty, but some anomalies of the karyotype may be detected whose consequences for the health of the child are unknown. When in doubt, physicians and parents may have differing attitudes about pursuing the pregnancy. After amniocentesis, a physician may refuse to terminate a pregnancy if this does not seem medically justified, but cannot force a woman to abort, even if from a medical viewpoint this seems acceptable. One could imagine similar scenarios in the case of prenatal genetic diagnosis (PGD), where a physician may refuse to initiate a pregnancy by not transferring affected embryos, but cannot impose a transfer against the woman's will (4).

A patient may legitimately question professional standards, as well as a physician's right to intervene in as personal a decision as whether or not to accept the birth of a child with a mental or physical deficiency. The physician him/herself may question this right to intervene. For in fact, medical and lay definitions of an acceptable risk, which frequently pit patients against physicians, also tend to overlap and eventually to conflict even in the physician's own reasoning: a physician's personal values with respect to the very sensitive problem of reproductive choices, also influence his/her professional attitudes<sup>vi</sup> (16).

What ultimately makes this problem such a troubling one is that, even if professionals are responsible for correctly establishing a probability of risk, once that risk is known, deciding what is an *acceptable* risk becomes a joint moral issue for all the protagonists involved. At length, it is also a social and policy issue because it requires deciding how far physicians may interfere in would-be parents' procreative decisions, to maintain their professional standards of risk-taking. Physicians are, after all, the present gatekeepers of reproductive technology.

### **3. To what extent is a physician accountable for the social conditions in which a child will be born?**

Beyond concern with donor screening, most countries

still honour a tradition, stemming from almost a century of practising DI, that allows parents—if they so desire—to conceal from family, friends and even the child, the means by which the child was conceived. This requires a policy of donor anonymity, but also selecting a donor whose physical traits match those of the would-be couple. Minimal matching involves controlling for such traits as skin colour (and in some cases hair and eye colour), as well as blood group. Proceeding in this manner makes it plausible to the ordinary observer that the parents conceived the child.

However, some donors have hereditary traits that do not justify exclusion but that could become markers revealing the parents' recourse to a donor procedure. Several genetic traits fall into this category, but each one poses different problems. A donor who is a known heterozygote for a recessive condition that neither of the parents have, has a 1 in 2 possibility of transmitting this trait to the child. However, this trait is not visible, at least in the first generation: at most, the child will himself or herself be a heterozygote for that condition and will therefore be healthy. A cleft palate and a harelip are also hereditary malformations; they are visible, but operable defects. But they do not necessarily function as markers, because sporadic (nongenetically determined) cases are also possible. On the other hand, a polydactyl donor (having more than the usual number of digits on the hands or feet) has a visible hereditary trait, which does not threaten the child's health but which indisputably acts as a marker of DI. Should such a donor be accepted?

Acceptance of such donors raises, as in our preceding dilemma, questions about the extent and the limits of genetic screening. Should physicians avoid the deliberate transmission of any harmful or anomalous genes; or should they attempt only to prevent the most disabling hereditary conditions? In the latter case, it must not be forgotten that evaluating the seriousness of a condition is never a totally objective procedure. Accepting such donors also presupposes that would-be parents are aware of the criteria that guide physician selection of donors in good health, and that they are ready to surpass the need for secrecy. And yet it has been this guarantee of secrecy that has allowed the practice to thrive and

<sup>vi</sup> An interesting international comparative study, directed by D. Wertz and J. Fletcher of the attitudes of clinical geneticists from 19 different countries confronted with a typical set of difficult cases, shows how values concerning medical decisions related to genetics, which often imply reproductive choices, vary from one society to another, as well as among individual practitioners, in particular according to their age, sex and religious practice.

to become socially acceptable, at least to a certain extent<sup>vii</sup>.

In associating, for reproductive purposes, two persons unknown to each other, who will not be recognized socially as the child's parents, the physician quite obviously plays a role that surpasses medical responsibility for correct implementation of a procedure. Paradoxically, this role as mediator in a morally delicate situation has always seemed self-evident. In recent years however, the psychological and moral validity of donor anonymity and of secrecy about the child's origins has been questioned. Semen banks in some countries offer nonidentifying information concerning donors and may even allow would-be parents to choose. Donated eggs are so difficult to obtain, that many physicians are now opting for nonanonymous donations, because women accept more willingly to undergo the risks of the procedure if the beneficiary is a friend or relative. These changes imply reconsidering the physician's role in donor procedures, as well as the criteria and purpose of screening and matching donors with recipients. Many of what may seem self-evident decision-making criteria are implicit suppositions about stable family life, child development, and concepts of health and normality. These must ultimately be submitted to open social discussion and some aspects of donor matching may call for policy decisions.

Questions about the physician's role and responsibility as mediator in a reproductive procedure also arise in nondonor procedures, in particular when an unforeseen incident changes the context in which assisted conception is being offered. One example is the unexpected death of the woman's husband or partner after treatment has been initiated (4). Sometimes frozen semen or embryos are still in storage and, on several occasions, women have requested the treatment be continued, alleging not only that this is their last chance to conceive, but that they wish to have the child of their deceased husband. Physicians' attitudes have varied and, in some cases, they have chosen to pursue treatment; but independently of the final action taken, concern has always been expressed about purposely favouring the birth of a child whose father is deceased. If the initial request was considered acceptable, to what extent, if at all, are the social conditions of a child's birth a physician's responsibility?

Most physicians do not restrict their evaluation of a medical indication for treatment to the physical symptoms. The choice of the most adequate treatment often takes into consideration a patient's finances, family surroundings, mental health, etc. In the case of assisted conception, the social condition of the would-be parents—married and in many countries cohabiting couples of acceptable procreative age—is part of the criteria defining the so-called medical indication. In this sense, the refusal of physicians to pursue treatment when the couple's social condition has changed (death or illness of one of the partners, divorce) appears to be a logical sequel to the initial stance. In this sense, our last dilemma returns to the first, the difference being that what appears as a socially unacceptable context arises from an unforeseen incident in a conventional situation, and not from the characteristics of the initial request.

## Conclusion

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What are the consequences for a society of having chosen to develop a medically mediated form of reproduction? The fact that would-be parents, whatever their social status, are asking physicians to provide the means of accomplishing what was once an intimate act is hardly an anodyne fact. Whatever the differences in technical variants, reproductive technology appears essentially to be "emancipating" procreation from the usual conditions of heterosexual commerce. Artificial insemination has long since desexualized the act of conception. IVF has now disembodied conception, a trend that could be extended to the rest of pregnancy by creating the conditions for ectogenesis. The prospect of cloning now augurs the emancipation of procreation from what still remains the fundamental requirement of sexual reproduction, the participation of sexually differentiated beings, and introduces the possibility of using reproductive cells (embryonic stem cells) for non-reproductive therapeutic purposes. What seems to be at stake in the development of these practices is a transformation of the anthropological conditions of procreation.

Should these new ways of conceiving become available to all persons who express a desire for

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vii The fact that secrecy is the most frequent attitude found among parents of children conceived with donor gametes belies the fact that this particular way of conceiving children and the kinship it establishes is not always perceived and experienced as legitimate.

children, or should they only be dispensed to persons in particular situations? Diverse variables affect both the ways in which the question is raised and the manner in which a society explores the reasons it has for implementing these techniques. Generally speaking, some countries favour a rights approach to issues of choice, giving more space to the political expression of atypical requests; others prefer an approach establishing the limits of what is socially permissible, devolving to physicians as professionals competent in reproduction the task of supervising the respect of these limits. However, the tendency to dissociate issues of reproductive freedom from the medical contexts in which they often arise tends to blind us to the constant interaction of issues of choice with matters of medical responsibility, as well as to the fact that the contours of professional competence and responsibility is a social and ethical issue in its own right.

This paper comes to no major conclusion as to the best way to proceed. How can it, when many of these issues are still emotionally charged objects of moral and political dissent? It does, however, distinguish some strong underlying trends in the development of these practices.

1. There seems to be a trend, even in conservative countries like France, to increasing acceptance of unconventional requests for assisted conception. This is happening, not through open political debate about rights and discrimination, but through the constant redefinition of what constitutes acceptable conditions for access to treatment, in particular through extensive interpretations of infertility and disease prevention.
2. Issues related to changes in the family are basically examined from the point of view of nonmedically motivated requests for assisted conception (single women and lesbians, menopausal women). Less attention is being given to the way medical reasons and, in particular, motives for genetic screening and diagnosis, are progressively shaping aspects of individual procreative choice. Mounting concern with the transmission of genetically determined conditions may have profound effects on the way persons meet and decide to have or not to have children, as well as the type of health care they seek. There may be significant differences between those who decide to take preventive measures and those who do not—differences that most certainly reflect the way persons deal with the disability that

afflicts their family.

3. These two trends are intimately linked to evolving conceptions of medical responsibility, an aspect of development in this area of medical practice that is far from getting the attention it needs. In some cases, physicians seem to be offering new options to persons who had no hope of having children; but they are also creating new constraints on procreative liberty. Some constraints imposed by a physician's concern with taking appropriate medical action may be based on valid arguments, pertinent to their field of competence (certain kinds of screening). Other constraints appear more questionable (limiting assisted conception to cases of infertility), but may occasionally derive from a social function attributed to physicians by society as part of the responsible exercise of his/her profession. All of these aspects merit close evaluation and, in the case of the latter, more open social and political debate. For as expectations grow regarding their technical competence and as the scope of their professional activity increases, physicians may, more often than not, be asked to make essential reproductive choices, even by the "patients" themselves.

## References

1. Becker G. *The elusive embryo: how men and women approach new reproductive technology*. Berkeley, University of California Press, 2000.
2. Nau J, "Un enfant a été créé par fécondation *in vitro* pour soigner sa soeur leucémique aux Etats-Unis, *Le Monde*, 5 octobre, 2000.
3. Robertson J. *Children of choice: freedom and the new reproductive technologies*. Princeton, Princeton University Press, 1994.
4. Bateman S, Novaes S, Salem T. Embedding the embryo. In: Harris J, Holm S, eds. *The future of human reproduction: ethics, choice and regulation*. Oxford University Press, 1998:101–126.
5. Novaes S. Giving, receiving, repaying: gamete donors and donor policies in Reproductive medicine. *International Journal for Technology Assessment in Health Care*, 1989, 5:639–657.
6. Fields J, Casper LM. America's families and living arrangements: March 2000. *Current Population Reports*. Washington, DC, U.S. Census Bureau, 2001:20–537.
7. Hanscomb GE, Foster J. *Rocking the cradle: lesbian mothers and the challenge in family living*. London, Peter Owen, 1981.
8. Cohen C, ed. *New ways of making babies: the case of*

- egg donation*. Bloomington, Indiana University Press, 1996.
9. Kolata G. "Babies born in experiments have genes from 3 People". *The New York Times*, May 5, 2001.
  10. Nau J-Y. "Des chercheurs américains sont accusés d'avoir conçu des enfants au patrimoine génétique modifié". *Le Monde*, 7 mai, 2001.
  11. Macklin R. Artificial means of reproduction and our understanding of the family. *Hastings Center Report*, 1991, **21**:5–11.
  12. Novaes S. *Les passeurs de gamètes*. Nancy, Presses Universitaires de Nancy, 1994.
  13. Novaes S. Beyond consensus about principles: decision-making by a Genetics Advisory Board in reproductive medicine. In: Bayertz K, ed. *The concept of moral consensus: the case of technological interventions into human reproduction*. Dordrecht, Kluwer Academic Publishers, 1994:207–221.
  14. Novaes S. Making decisions about someone else's offspring: geneticists and reproductive technology. In: Fortun M, Mendelsohn E., eds. *The practices of human genetics*. Dordrecht, Kluwer Academic Publishers, 1998:169–184.
  15. Novaes S. Éthique et débat public: de la responsabilité médicale en matière de procréation assistée. In: Cottureau A, Ladrière P (sous la direction de). *Pouvoir et légitimité: figures de l'espace public*. Paris, Éditions de l'EHESS, 1992, **3**:155–176.
  16. Wertz DC, Fletcher JC. *Ethics and human genetics: a cross-cultural perspective*. Berlin and Heidelberg, Springer-Verlag, 1989.